

Caring for Families of High-Risk Infants

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THE USE OF intensive care nurseries has caused a major improvement in the quality of care for ill newborn infants and has resulted in a lowering of neonatal mortality. This drop in mortality has been in addition to a decrease in the long-term morbidity of premature and term infants.¹⁻⁴ Continuing research and application of newer discoveries are responsible, as well as the rapid dissemination of this information from one facility to the next. Although the specific details of managing certain classes of problems such as hyaline membrane disease, hypoglycemia and erythroblastosis may vary from one institution to another, the general protocols involved and methods of approach and treatment are fast becoming standard. At present the similarities are greater than the differences.

However, one great variability remains in the interaction of family, specifically the parents, and the medical personnel involved in the case of an acutely ill neonate. In fact, different approaches to such interaction may be seen not only from facility to facility but also within the same hospital. A standard approach, as used for an acute medical problem, has not been developed for the care and attention delivered to the families involved. There is evidence, though, that attempts are being made to achieve that goal.⁵⁻¹⁰

The causes of the problem are many and do not necessarily result from reluctance by medical

staffs to establish communication with parents. In fact, many causes of the problem stem from parental hesitations. Inadequate interaction between parents and staff that can be traced to the parents may be the result of (1) an actual desire by parents not to be made aware of the severity of the problems involving their baby or a denial that a threat to life exists, (2) each parent, wishing to protect the other from potentially distressing news, may choose not to solicit any information from the staff and (3) there may be a desire by the parents, as recovery occurs and survival becomes apparent, to remain uninformed about early critical events in the life of their baby because of the threat it poses to the baby's future growth and later development.

Similarly, the medical staff may show hesitancy in talking freely with parents for many reasons: (1) the difficulty physicians and nursing staffs have in expressing probabilities to parents—that is, even though they may be hopeful of survival there remains the constant threat of death, (2) with recovery there is a tendency to become more involved with insuring that the baby is thriving and that the parents should be more concerned with the daily feeding and care problems than the difficulties through which the baby passed perinatally and (3) finally and most important, there may be a lack of knowledge by house staff members as to what long-term “quality of survival” can be expected for infants who have had serious and life threatening perinatal experiences and who have been cared for in newborn intensive care units.

The goal of this paper is to present these problems of parent-medical staff interaction and to

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discuss one technique used in an attempt to resolve them. Opening up discussion between parents and medical personnel is not a unique endeavor. However, this report is intended to alert physicians to those factors that might not be freely spoken of by parents and yet underlie their concerns. The following case history will serve to keynote the discussion.

Report of a Case

Bobby T. was born weighing 1.02 kg, at a gestational age of 28 weeks, to Mrs. T. who was Gr III P II Ab O. The pregnancy was uncomplicated. Premature labor had led to the use of an alcohol infusion without result and birth occurred 36 hours later. Apgar scores were 1 and 0 at one and five minutes respectively. Resuscitation with endotracheal intubation, umbilical artery catheterization, and fluid and bicarbonate infusion restored the baby's pulse and color. Mechanically assisted respiration was required for the first 24 hours and oxygen for the next ten days. During this time the baby's course was complicated by hypoglycemia (necessitating treatment), apnea, abnormal spontaneous movements of arms and legs (described as seizures), a weight loss of 10 percent and possible sepsis. Cultures of blood, urine and cerebrospinal fluid were therefore made and treatment begun with antibiotics. Gavage feedings were started at 5 days of age. By 2 weeks of age his weight loss ceased, the abnormal movements of arms and legs had come to a halt, the cultures had returned negative and it was apparent that recovery was assured.

At this time it was also clear that the family was experiencing difficulty. Mrs. T. in fact had been alone through much of the labor and delivery, being visited only occasionally by a friend. Her husband, out of state on business at the time, had not been able to be present. Even after Bobby's birth he returned to the city only for a brief visit and then left again to resume his activity as before. Therefore, the burden of the early days was forced upon Mrs. T. without support from her family. Before her discharge she saw the baby once and then went home for a period of rest. During the baby's early crises, the family's interactions were entirely by telephone and then only once every three days. The mother did finally join her husband on his business trip. It became apparent later that the family's difficulties at this stage were a reflection of their concern and

not an attempt to ignore the seriousness of the situation.

Because of its program involving premature infants at the University of California at Los Angeles, the Division of Child Development became involved after the baby entered his recovery phase. Initial contact with the family was made by a nursery social worker following their return to this city. There was great reluctance by the mother to visit the baby; illness was frequently cited as the reason. Mr. T. in fact saw the baby only at discharge, a situation created, he stated, by the demands of his occupation.

The initial goals of the physician and nurse from Child Development were to be supportive at this time not only of the family but also of the house staff and nurses caring for the infant. As the baby improved and did well, it was possible to reassure them and to point out the positive features of the baby's behavior. Mrs. T. was told that even though all her initial questions could not be answered, others recognized her concerns and would attempt to provide answers as they became known. At this time her anxiety peaked and questions about placing the baby in a "mental institution" were raised even though the baby had begun to thrive.

The first time Mrs. T. saw Bobby close-up and held him was six weeks after she herself had left the hospital. It took a good deal of encouragement to help her make the first overture toward him. On subsequent visits to the nursery, she brought someone who was to help care for him—it was her intention to allow her domestic servant to be the person who would care for the child primarily. This of course complicated the task of helping Mrs. T. make an attachment to her baby. As the public health nurse became more involved with the family a good deal of listening was required. At the same time strengths were looked for in both Bobby and Mrs. T. that could be pointed out to her. The special care needed for a premature infant was discussed without overemphasizing potential problems. The physician and nurse made themselves available to the family as needed in order to support their efforts and answer their questions.

On the day of discharge the physician-nurse team had the opportunity to see Mr. and Mrs. T. together. There appeared to be very little physical or emotional support from Mr. T., a fact confirmed by his wife in subsequent interviews. Mrs. T. took Bobby home alone that day and Mr. T.

went on to work. Mrs. T. was encouraged to call whenever necessary and it was agreed that the nurse would phone her the following day.

During that conversation the next day, Mrs. T. indicated that she had already taken on the role of primary provider of care. Actually, she and her servant alternately handled the night feedings. As she cared for Bobby it was possible for her to observe what his strengths were and she derived a good deal of pleasure from this.

The first few weeks that the baby was at home were without difficulty. He slept well and his feedings were normal. However, in the ensuing months his crying became more demanding and Mrs. T. found this very difficult to tolerate. Feelings of hostility surfaced, but because of her relationship to the physician-nurse team she was able to express this hostility openly with them. They in turn were able to appreciate the stresses with which she was dealing. As Bobby grew, it was apparent that his development was indeed normal both mentally and behaviorally. This was discussed with his mother and she was encouraged to proceed with plans to develop her own free time and do some of the things she enjoyed. In this way she was better able to tolerate the difficult times and to enjoy the pleasant times she and Bobby had together.

Results of formal testing of Bobby have shown no evidence of handicap: at four months of age the Gesell development quotient was 106, at 9 months it was 90. A cognitive examination at nine months of age based on the Piaget sensorimotor scheme was felt to give normal findings. With time the frequency of home visits by the nurse and appointments at the clinic with a pediatrician decreased in number as the family was able to assume more and more of the responsibility of observing Bobby's behavior and arriving at healthy techniques in managing his normal problems themselves.

It is recognized that this family has had difficulties and in all likelihood will continue to have them. It is possible that they will need more active intervention in the future, but the goal of allowing the baby to achieve full potential was realized. The attachment of the parents to their baby was aided at a time that was felt to be crucial to his development. Mrs. T., in fact, was able to see strengths in herself that she had not been aware of before. Also her ability to observe behaviors in her son and to appreciate his development grew remarkably.

Discussion

Using this case history as a model, it is possible to identify overlapping stages of parent-staff interactions. These indicate what parental concerns exist during the various periods of the infant's development. In order to present our goals some brief description of these phases is in order.

Acute Phase—This period immediately follows birth and encompasses the major events affecting an ill newborn infant. It is the time when there is realistic concern about survival. It is also the time when little may be explained to the mother.

The father, because of work, obligations to other children or other reasons, may not be available for discussion. The parents may not press the staff for information and as a result little exchange may occur. In the case of Bobby the family in fact chose not to be present at all. Their reluctance to visit, however, was actually a sign that they truly appreciated the seriousness of their baby's condition.

Recovery Phase—It has now become apparent that the baby will survive. However, the parents may not ask to be told what the baby has passed through. Conversely, the medical staff may not want to discuss those events in detail because they may not feel secure in relating them to outcome. In fact both sides may feel that a baby who has survived such serious events cannot possibly be normal. These worries may not be put in words by either side. Mrs. T.'s questions during this period about placement of the baby in a mental institution reflected her anxiety about these events.

Discharge Phase—Questions about the future remain but suddenly the potential burden of day-to-day care becomes a major factor. Preparations for feeding, dressing and bathing are made and discharge is contemplated. The impact of providing for a baby who nearly died but survived—and who may be presumed by the parents to be defective—is a major undertaking. Upon discharge the mother may be given an appointment to the Well Baby Clinic, to a city clinic or occasionally to the office of a private physician. In the former two situations, the family will be forced to adjust to health personnel with whom there has been no earlier contact.¹²

Postdischarge Phase—The full impact of providing care for the infant is suddenly upon the family, predominantly the mother. Frequent daily disruptions which are distressing in the normal

situation may be exaggerated out of proportion. To a parent, crying by the infant may represent defective behavior; spitting-up may bring back the earlier concerns in the nursery when so much effort was centered around the feedings. Quite often the family will begin to see the child as extremely vulnerable—a pattern that may be difficult to reverse in the months to come.¹³

Long-Term Follow-up Phase—With the continued support offered by a physician and a nurse, and the usual normal development of the infant, this period will find parental fears relaxing. However, it is not uncommon for feelings about the vulnerability of their child to persist for months and years. The physician and nurse will find it necessary not to demand an unrealistic resolution of all parental concerns but rather to hope to see gradual control over them develop.

The role of the physician and nurse who will care for the baby after discharge is guided by a single goal: to provide the most optimal circumstances in which the baby might thrive and develop to the fullest potential. The expression of this goal depends on the family and the type of concern it is experiencing. This leads us to a discussion of the role of the physician and nurse.

The Nurse's Role

A public health nurse skilled in the area of child development has a unique opportunity to provide true continuity of care. Parent-nurse interaction begins before discharge but becomes very important when the infant is at home. No other member of the health personnel group is in such a position to provide this help.

Within the nursery, such things as crying, startle responses and difficulties in feeding are handled casually by the house staff and an intensive care unit nurse. As a result the mother may truly not have the opportunity to clarify her questions about such patterns of behavior. At home she may question whether they represent abnormalities. The misinterpretation of normal crying is often made by parents. Until the family returns to the pediatrician for an initial examination of the infant, enough time may pass to allow for the creation of aberrant maternal responses and difficulty in the interaction between infant and mother.¹⁴ This period, therefore, demands that attention from a trained observer be available early and that constructive intervention be applied to prevent the occurrence and persistence of these maladaptive patterns.

Initially then, these issues of behavior by the infant and what it represents can be discussed. That the infant has in fact developed can be shown; problem areas, be they behavioral such as crying or related to day-to-day management, can be given attention that takes into account the mother's ability and her perception of the difficulties, and the nurse's experience.

On subsequent clinic visits, the nurse can meet with the family along with the physician. Questions that they may find difficult to ask the physician can be encouraged openly by the nurse. With time, the frequency of nurse visits to the home may vary. In those situations where early problems are resolved comfortably, they will usually decrease.

The Physician's Role

During the initial stage of the acute postnatal events in the intensive care unit, a physician from the child development clinic may not be involved with the family, but by being present in the nursery it will be possible for him to discuss the significance of perinatal problems with house staff and their relationship to subsequent development. Because current reports strongly suggest that the intensive care provided for sick neonates is lowering morbidity, the child development physician will have the opportunity to encourage the continuation of care. It is important to emphasize that this support be directed not only to the house staff involved but also to the nursing personnel, who are usually in frequent contact with the parents.

As the condition of the baby improves, an initial approach to the family can be made. Questions about prognosis are often heard, but because of the nature of the situation many of these questions cannot be answered. It is also apparent that parents are not always asking for specific answers, but rather are seeking an opportunity to voice their anxieties. The physician, in turn, can show willingness to share these worries and to assure the family that as the answers become known they will be supplied. It is important to allow the parents to meet the public health or child development nurse at this time. In fact, the nurse's role becomes vital as discharge approaches. The physician arranges follow-up appointments and provides the family with a means to contact him should it be necessary.

Later as the baby matures, the answers to the parents' early questions will become available.

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The unknown factors gradually will be dealt with. In those situations where handicapping conditions arise—either within the child or within the family—they can be handled appropriately by the physician and nurse because of their knowledge of the people involved.

Conclusions

In medicine, as elsewhere, it is uncommon to find a sequence of events fall into set patterns. Certainly the periods outlined here do not occur separately. Rather, there is great overlap; concerns over life and death may be expressed months after birth or the fear of brain damage may be present even within a few days of delivery. Our purpose in identifying specific phases is to encourage physicians and nurses to think about what the families of their patients may be considering and what may enter into their interactions with the medical staff. We have found that the presence in the nursery of personnel who are familiar and comfortable with the data on long-term outcome does not inhibit discussion between house staff and parents—but in fact promotes it. Further, the continuity provided by having the outpatient physician and nurse meet the family before discharge of the infant is im-

portant. It is to be hoped that in the future house staff might in fact be able to assume this role as they become more aware of the improving outcomes for patients cared for in nursery intensive care units.

REFERENCES

1. Davies PA, Tizard JPM: Very low birthweight and subsequent neurological defect. *Dev Med Child Neurol* 17:3-17, 1975
2. Fitzhardinge PM, Ramsey M: The improving outlook for the small prematurely born infant. *Dev Med Child Neurol* 15:447-459, 1973
3. Dweck HS, Saxon SA, Benton JW, et al: Early development of the tiny premature infant. *Am J Dis Child* 126:28-34, Jul 1973
4. Wright FH, Blough RR, Chamberlain A, et al: A controlled follow-up study of small prematures born from 1952 through 1956. *Am J Dis Child* 124:506-521, Oct 1972
5. Klaus M, Kennell J: Care of the mother, chapter 7. In Klaus M, Fanaroff A: *Care of the High Risk Neonate*. Philadelphia, W. B. Saunders, 1973, pp 98-118
6. Barrett C, Leiderman P, Grobstein R, et al: Neonatal separation—The maternal side of interactional deprivation. *Pediatrics* 45:197-205, Feb 1970
7. Leiderman PH: Mothers at risk—A potential consequence of the hospital care of the premature infant. In Anthony EJ, Koupernik C (Eds): *The Child in His Family—Yearbook of the Inter. Assoc. for Child Psychiatrists and Allied Professions*, Vol. III. New York, Wiley, 1974, pp 149-156
8. Kennell J, Rolnick A: Discussing problems in newborn babies with their parents. *Pediatrics* 26:832-838, Nov 1960
9. Asch SS, Rubin LJ: Postpartum reactions—Some unrecognized variations. *Am J Psychiatry* 131:870-874, Aug 1974
10. Klaus MH, Jerauld R, Kreger NC, et al: Maternal attachment. *N Engl J Med* 286:460-463, Mar 2, 1972
11. Newton N, Newton M: Mothers' reactions to their newborn babies. *JAMA* 181:206-210, Jul 21, 1962
12. Becker MH, Drachman RH, Kirscht JP: Continuity of pediatrician: New support for an old shibboleth. *J Pediatr* 84:599-605, Apr 1974
13. Green M, Solnit A: Reactions to the threatened loss of a child—A vulnerable child syndrome. *Pediatrics* 34:58-66, Jul 1964
14. Brazelton T: The early mother infant adjustment. *Pediatrics* 32:931-937, Nov 1963